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ABSTRACT

This paper provides a framework for making sense of perplexing problems surrounding issues of death and dying by exploring the theological and ethical background to health care decision making at the end of life. The paper first examines several of the basic principles that theologians and secular ethicists employ when analyzing such questions. These fundamental principles include respect for life; autonomy; do no harm; do good; and justice. The paper then goes on to examine three critical distinctions that theologians and ethicists employ when confronting the ethics of death and dying in concrete cases: (1) the distinction between the direct and indirect effects of an action; (2) the distinction between ordinary and extraordinary means of treatment; and (3) the distinction between killing and letting die. The stated intent is to provide the reader with an understanding of the basic analytical tools of medical ethics, and thereby help the reader become an informed participant in the debates about health care decision making at the end of life. The paper concludes that, in making health care decisions at the end of life, life should be preserved and promoted, but there are times when it is morally appropriate to permit someone to die rather engage in a futile holding action against death. (Author/ABL)

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HEALTH CARE DECISONS AT THE END OF LIFE: THEOLOGICAL AND ETHICAL FOUNDATIONS FOR DECISION MAKING

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ABSTRACT

Title: Health Care Decisions At The End of Life: Theological And Ethical Foundations For Decision Making

Synopsis: Issues of death and dying raise some of the most perplexing problems in medical ethics. This paper provides a framework for making sense of these problems, by exploring the theological and ethical background to health care decision making at the end of life. The paper first examines several of the basic principles that theologians and secular ethicists employ when analyzing such questions. These fundamental principles include respect for life; autonomy; do no harm; do good; and justice. The paper then goes on to examine three critical distinctions that theologians and ethicists employ when confronting the ethics of death and dying in concrete cases: The distinction between the direct and indirect effects of an action; the distinction between ordinary and extraordinary means of treatment; and the distinction between killing and letting die. The intent is to provide the reader with some understanding of the basic analytical tools of medical ethics, and thereby help the reader become an informed participant in the debates about health care decision making at the end of life.

HEALTH CARE DECISIONS AT THE END OF LIFE:
THEOLOGICAL AND ETHICAL FOUNDATIONS FOR DECISION MAKING

In order to make wise decisions about health care, we need some sense of the way to approach the decisions. We can hardly decide whether to agree to have medical treatment withheld from a dying parent, say, without first reflecting upon the needs and desires of our parent, our own perspectives on the meaning of life and death, and so on. In this paper I will present a theological and philosophical framework for approaching health care decisions at the end of life. I will divide my remarks into two parts. First, I will discuss several basic principles that Christian theologians and secular ethicists employ as they analyze medical ethical issues. Second, I will go on to examine several critical distinctions that they use when dealing with health care decisions at the end of life.

Basic Principles of Medical Ethics

Theologians and secular ethicists employ a wide variety of analytical tools to help them think clearly and precisely about medical ethics. Among the most important of these basic principles are the following: respect for life; autonomy; do no harm; do good; and justice. I will discuss each briefly.

Respect for life. Almost everyone agrees that life is a great good that should normally be preserved and promoted.

Sometimes this understanding is termed respect for life, sometimes reverence for life or the sanctity of life.

Theologians often talk of life as a gift of God. Men and women are made in the image and likeness of God. God is the creator and lord of life.

Secular ethicists often talk of life as the value that makes all other values possible. Persons are not mere things but ends in themselves. They are of unconditional worth and dignity.

This intuitive appreciation of the value of human life leads to a broad consensus among medical ethicists (a consensus, I should add, that is held by most in the wider society as well): innocent life should not be directly taken. Killing is justified, if at all, only in the cases of self-defense, just wars, etc. There is strident debate about who should be protected by this general prohibition on killing. What about abortion? What about animal rights? But most theologians and secular ethicists agree that mercy killing (actively killing someone to put her out of her pain or suffering) is wrong. Likewise, most argue that suicide is wrong. Although it is not usually a crime anymore to attempt suicide, theologians argue that only the God who gives us life can call us out of life, and secular ethicists point out the contradiction of a free person using her freedom to destroy it.

On the other hand, the consensus in favor of respect for life does not entail a commitment to life as the highest or ultimate value. Theologians note that loyalty to God is more

important. We must beware of making an idol out of life. Death is an evil but also the doorway to eternal life. The willingness of Jesus to submit to death serves as a model for his followers. Thus the Christian tradition recognizes that there are times when it is appropriate to let someone die, that not all measures must be taken in a vain effort to forestall death.

Secular ethicists often hold a similar view. They recognize that there are times when life can be sacrificed for other ends, such as liberty. Consider a just war.

In sum, there is a broad agreement that life is a basic good but not the only good. The principle of respect for life pushes us toward protecting and promoting life. It gives us a "bias" towards life. But respect for life also entails an appreciation of the limits of our commitment to preserve life.

Autonomy. Another important principle of medical ethics is autonomy. Autonomy means self-rule or self-government. Theologians talk of the individual's personal responsibility to follow God as she sees fit. Secular ethicists say that persons are ends in themselves and therefore each person must make her own rules for living.

This leads to another broad consensus: Assuming a person is competent, her decisions normally should be honored by others. Autonomous choices should not be limited by other persons. Of course, there are limits to autonomy. Your autonomy ends where my nose begins. A promise to another person can limit my autonomy. And there is the persistent problem of how to deal

with the incompetent, those unable to decide for themselves.

Still, the principle of autonomy is central to our reasoning about health care decision making. It means that in most cases the decisions of an adult should be respected, whether the decision is to have all efforts made to postpone death, or whether the decision is to withhold or withdraw life-sustaining treatment.

Notice the tension between our first two principles. The principle of respect for life argues against suicide, while the principle of autonomy might argue for the right of each person to decide. Likewise, in debates over euthanasia, those who are strongly committed to the principle of respect for life are often the most vigorous opponents of so-called "mercy killing." Those who place great stress on promoting autonomy, however, are more inclined to permit euthanasia when the patient freely decides to die. The first principle pushes us toward protecting life, while the second leaves the decision in the hands of the patient.

These are probably the most important principles at work in discussions of health care decisions at the end of life. Several others should be briefly mentioned.

Do no harm. This principle reflects a basic maxim of medicine. "First, do no harm." It also reflects a moral intuition held by most persons. It is wrong to inflict evil on others. We should try to minimize the amount of pain and suffering we cause to others.

When we attempt to apply this maxim to medical decisions at

the end of life, we immediately confront the problem: What precisely is the harm we are trying to avoid? Consider a dying man being kept alive on the most modern life-sustaining technology. Which is the harm: keeping the patient alive indefinitely, despite his great pain, or letting the man die when we could keep him alive?

Do good. This is another basic maxim of medical ethics and ordinary life. Try to help others when you can. Do what you can to cure them and alleviate their suffering.

Again, note the problem that arises when we attempt to apply the maxim to health care decisions at the end of life. Are we doing good when we keep a person alive a little longer, or when we let the person die? Often the principle of doing good forces us to compare the costs and benefits of a certain treatment. What are the burdens of the treatment, what are the benefits? This raises an intractable problem. How do we even begin to balance the costs and benefits of keeping a person alive or letting the person die?

Justice. Justice is giving each person her due. In medicine, questions of justice often involve the allocation of resources. Is it just, is it fair, to spend thousands of dollars to keep alive one person on a respirator, or should the money be used instead to provide prenatal care for hundreds of pregnant women living in poverty? If there are two persons who both need a scarce drug, but only one can receive it, who will make the decision? And what criteria will they use to make it?

These principles will not give us easy answers to the hard problems that arise at the end of life, but they do provide the theological and ethical backdrop for wrestling with the problems. I now want to turn to several critical distinctions that theologians and secular ethicists employ. In a sense, these are applications of our basic principles. They are more concrete and less abstract than the principles, and are meant to provide moral guidance for those who must make health care decisions at the end of life.

Basic Distinctions in Medical Ethics

There are three important distinctions that are relevant to medical ethics decision making. They are the distinction between the direct and indirect effects of actions; the distinction between ordinary and extraordinary means of treatment; and the distinction between killing and letting die.

Direct and indirect effects. The distinction between the direct and indirect effects of an action is founded on the common sense notion that an action may be taken for the best of reasons yet have both a beneficial and a harmful effect. In Roman Catholic theology, where the distinction was originally developed, it is a well-established principle that innocent life cannot be directly taken. Yet it is also recognized that sometimes death can be the unintended side-effect of a morally acceptable action. For example, Roman Catholic theology accepts

that a person in great pain can be given pain-killers even though death might result. The intent was to do something good--to alleviate pain. Death is the unfortunate and unintended or indirect side-effect. Thus the morality of the action depends upon the intent of the actor.

Catholics and others have elaborated upon this basic distinction in the principle of the "double effect." In order for an action that has both good and bad effects to be morally permissible, four conditions must be met: (1) The act in itself must be good or at least not evil. (2) The actor must intend only the good effect. The evil effect is not intended, but only foreseen and allowed. (3) The evil side-effect cannot be the means to the good effect. The good and evil effects must both follow immediately from the action. (4) The good intended must be proportionate to the evil allowed (T.Beauchamp and J.Childress, Principles of Biomedical Ethics, 2d ed., Oxford, 1983, p.113). Under this reasoning, Catholic teaching holds that a cancerous uterus can be removed from a pregnant woman, despite the foreseeable death to the fetus, and despite the Church's opposition to abortion. The death of the fetus is said to be unintended and indirect.

For our purposes, the important point is that the distinction between direct and indirect effects recognizes that there are times when it is ethically permissible to do good even though death may result. It is not necessary to keep a person alive regardless of the costs. Although it is wrong to intend

directly to take life, it is not wrong to do good when death is the unintended effect.

Ordinary and extraordinary means. This distinction also developed originally in Roman Catholic thinking, but is now widely used by others, including courts of law. In 1973, for example, the American Medical Association held that a patient and her immediate family have a right to refuse extraordinary means of treatment, when it is clear that death is imminent (Beauchamp and Childress, p.126).

The distinction between ordinary and extraordinary means is actually a distinction between required and optional forms of treatment. Only ordinary treatments are obligatory; extraordinary treatments may be used, but need not be. Ordinary means include all medicines and treatments that offer a reasonable hope of benefit and can be used without excessive expense or pain or other inconvenience. Extraordinary means include all medicines and treatments that do not offer a reasonable hope of benefit or that cannot be used without excessive expense or pain or inconvenience (Beauchamp and Childress, p.127).

It is by no means clear what constitutes a "reasonable hope of benefit" or an "excessive" pain or burden. These are difficult issues that cannot be answered in the abstract, but demand a thorough examination of the particular situation. But the distinction is important because it acknowledges that not all available treatments must always be used. If a treatment in a

particular case would be pointless, or would have too many negative consequences, it may be withheld or withdrawn.

It therefore becomes critical in each case to balance the benefits and costs of the treatment as they affect this patient. No treatment is always ordinary, even if it is medically customary. A respirator or a feeding tube or chemotherapy--even an IV--may be ordinary and hence required in one case, and extraordinary and hence optional in another. It is the effort to grapple with the benefits and burdens of treatments in particular cases that forces health care professionals and patients and courts to confront difficult questions of the "quality of life."

For our purposes, the distinction captures the common sense notion that life is to be preserved but not at all costs (Consider our earlier discussion of respect for life). Death is to resisted, but not when resistance is pointless or would cause more bad than good.

Killing and letting die. Most theologians and secular ethicists insist that there is a crucial distinction between killing someone and letting a person die. The first is morally impermissible, the latter permissible.

A few ethicists argue that there is no real difference. What is the moral difference between, say, killing my wealthy aunt for her money, or watching her drown to death while doing nothing to save her?

While it may well be true that I am equally blameworthy in our two examples, this does not mean that the distinction between

killing and letting die is without merit. Recall our earlier discussion of the principle of respect for life. That principle opposes the direct killing of innocent life, but does not require preserving life at all cost. So too the distinctions between direct and indirect effects, and between ordinary and extraordinary means, acknowledge that there are times when it is morally permissible to allow someone to die. In such cases, the intent is not to cause the patient's death, but to allow the disease to take its course and to cease exposing the patient to needless pain and suffering.

There are other reasons in support of a distinction between killing and letting die. If we are to respect a person's autonomy, we must allow that person the freedom to say "no" to treatments that serve no purpose but to prolong an inevitable death. Most theologians and ethicists agree that the decision to say "no" to life-sustaining procedures is not the moral equivalent of suicide.

Furthermore, when life-sustaining treatment is withheld or withdrawn, the cause of death is the underlying medical condition. If we were to permit active killing of patients, however, the cause of death would be the act of the doctor or other "mercy killer."

Finally, many argue that the distinction is necessary to avoid the harmful consequences that would ensue if killing were sanctioned by society. Think, for example, of the effects on the doctor-patient relationship if terminally ill patients knew that

their doctor might also be their executioner. Consider the wider social implications. Who would stand the most to lose from a social policy permitting killing of the sick? Would it not be the poor, the disadvantaged, the handicapped? Would the door not be opened to the extermination of social "deviants," as happened in Nazi Germany? For all these reasons, it makes good sense to prohibit killing, even if in a particular case we might be able to understand or empathize with the person who kills a loved one rather that see the loved one suffer.

In short, most theologians and secular ethicists (and most ordinary people as well!) reject active killing, but recognize that life-support systems may be withheld or withdrawn in certain cases, where the treatment is pointless or where its burdens outweigh its benefits for the dying patient.

Thus, all three of our distinctions lead to the same conclusion: In making health-care decisions at the end of life, life should be preserved and promoted, but there are times when it is morally appropriate to permit someone to die rather than engage in a futile holding action against death. The principle of autonomy should also be mentioned here: If the patient is competent, the decision about whether to accept or reject life-sustaining measures should normally be made by the patient. Of course, some of the most difficult cases will arise when the patient is not competent. Who should decide for the old person in a coma, or the newborn, or the dying patient who has never been competent? And even if we can agree on <u>who</u> is to decide,

how should they make their decision? What standards or rules should guide them?

These and other difficult questions remain unresolved. The principles and distinctions examined in this paper provide a framework for thinking about these problems. They provide a foundation, a starting point for ethical reflection. But it should be clear by now that they cannot provide simple answers to the hard questions that arise at the end of life. In this area, as elsewhere, there are no simple answers to be had.

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